

ILHIE Data Security & Privacy Committee

Invited Public Testimony

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Panel 5: Patient Choice and Consent: Operational Protocols

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Achieving patient “meaningful choice”

Meaningful Choice defined:

- 1. Made with advance knowledge/time;**
- 2. Not used for discriminatory purposes or as condition for receiving medical treatment;**
- 3. Made with full transparency and education;**
- 4. Commensurate with circumstances for why IHI is exchanged;**
- 5. Consistent with patient expectations;**
- 6. Revocable at any time.**

HIPAA Privacy Rule permits

CE permitted to use & disclose PHI for certain activities:

- Treatment
- Payment
- Health Care Operations

HIE Consent Models

- **“Opt-in”**
- **“Opt-in with restrictions”**
- **“Opt-out”**
- **“Opt-out with exceptions”**

Challenges facing the HIE

- **Lack of formally defined consensus based confidentiality codes denoting sensitive data.**
- **Challenge of training registration staff to deliver a consistent “meaningful choice” consent message.**
- **Lack of consistent patient health literacy levels.**
- **Lack of consistent patient technology literacy levels.**
- **Lack of EHR based on Structured Data.**
- **Immaturity of security safeguards**

Initial steps to the preferred future

- Develop an HIE HIPAA Privacy policy for consumers to review, outlining the obligations with which HIO/HIE initiative participants and providers are required to comply.
- Develop consumer education relating to “Opt-in and “Opt-out” methods of specifying consent and data sharing preferences.
- Develop education for providers to familiarize them with the best technical practices regarding information exchange and relevant agreements.
- Design and implement appropriate and ongoing education programs to provide HIO/HIE initiative participants with knowledge about good security practices that include

“opt-out” “meaningful choice” consent process

- Opportunity to change their consent status with each new encounter.
- Patient provided with educational brochure containing a form.
- Web site access to patient support line.
- Formal consent model education and training.
- Multiple point of care options to modify their consent status.
- All consent preferences are routed directly thru HIE organization.
- Master patient index – Limited demographic information/no clinical information.
- Opt-out confirmation letters sent weekly.
- Electronic track process to track patients who decide to opt back into the HIE.
- Audit process to check accuracy of the patients consent preference.
- Audit of the “meaningful choice” consent process. monitor & mitigate variation in consent process

Should all consents be written Or can consent be obtained orally?

- E-SIGN (Electronic Signatures in Global and National Commerce) Act
- UETA (Uniform Electronic Transactions Act)
- An emergency disclosure to avert an imminent threat to safety § 164.512(j)(1)(i)

***Once consent is validly obtained,
is it valid for an unlimited duration of time?***

- The Privacy Rule requires that an Authorization contain either an expiration date or an expiration event that relates to the individual or the purpose of the use or disclosure.
- An Authorization remains valid until its expiration date or event, unless effectively revoked in writing by the individual before that date or event.

Or can it be revoked after a certain amount of time?

- Authorization contains a statement informing the individual regarding the right to revoke the authorization in writing and a description how to do so.

If consent can be revoked how should providers reconcile conflicting patient consents?

A formal consent directive application:

- Allows users to create, store, amend, and replace a consumer preference;
- Transmit the preference electronically;
- Allow for individual providers and other exchange participants to view the preference;
- Apply the preference to an individual health record;
- Transmit an update of the preference;
- Reconcile conflicting preferences; maintain an audit log of the preference; and classify data.